



Rehearsal Guide

Sleep Study

Preparing people with intellectual disability/autism (ID/A) to successfully complete a sleep study

Introduction for Caregivers

A rehearsal guide contains realistic pictures, concrete ideas, and clear, brief instructions for guiding a person through what can be expected in a specific situation. It includes helpful suggestions for caregivers to follow to make the experience meaningful for the person and increase the likelihood of a successful outcome. This approach is beneficial when supporting people with intellectual disability/autism (ID/A) who are anxious about situations such as doctors' appointments, hospitalizations, and medical testing.

A rehearsal guide provides opportunities for the caregiver to assist the person to learn about a specific situation. It contains information on what is needed and why and explains exactly what can be expected. Such a guide is most effective when it is person-centered and used in conjunction with discussion to allow exploration of specific areas of concern. It can be a powerful tool when used as intended.

The expected result is that the person will then experience the situation in a way that supports health and well-being by being prepared and knowing what to expect. The guide can be used at all stages of the situation to facilitate a positive end result.

Thank you for taking the time to use this tool to work with self-advocates to improve their health outcomes.

How to Use This Rehearsal Guide

For best results, begin to review this rehearsal guide with the person prior to the day of the appointment. Sometimes it will help to review this material with an individual several days or weeks before an appointment; other times, it may be better to wait to review this material until just before the procedure is to take place, perhaps the day before or the morning of the procedure. Together with the individual, determine which will best suit the individual's needs and abilities in understanding the information provided; however, it is important not to wait until 5 minutes before a procedure to introduce this guide to an individual. Give the individual enough time in advance to become familiar with the procedure based on the pictures and information contained on each page and with the individual's abilities in mind.

It is best to review this guide slowly and to focus on one idea/page at a time, allowing the person to talk and/or ask questions after each idea/page is presented. A caregiver may want to share personal experiences related to having this procedure done but be sure to do so in a positive manner, depicting a positive outcome.

For Best Practices

- ✓ Allot time to review this material when the individual is alert and interested in doing so.
- ✓ Ensure that the setting is free from distraction. Based on the individual's attention span, it may be best to review one page at a time, rather than reviewing an entire guide in one sitting.
- ✓ Explain each picture and practice the suggested exercises with the individual, such as deep breathing, as they appear throughout the guide.
- ✓ On the day of the procedure, take this guide along to continue rehearsing the various steps involved in the procedure. Review each page step by step.
- ✓ Remain positive, calm, and upbeat.
- ✓ Remember to offer positive reinforcement throughout the procedure. If the procedure is not able to be completed, focus on positive aspects. If the individual seems upset, talk about it later when they are calm to find out how they felt and what could be changed or improved to have a better outcome the next time.

Introducing the Process

(Name of individual), you are going to have a Sleep Study on *(insert date here)* at *(name of location)*.

The doctor ordered this test for you because *(state reason here – such as, you have not been sleeping well, you are tired during the day, etc.)*.

This test can help the doctor to keep you healthy.

(Name of caregiver) will go with you and help you get settled in your room.



What Not to Eat or Drink

On the day of your study, your doctor will probably tell you not to eat any foods or drinks with caffeine. That's because caffeine can make it hard for you to sleep.

That means no coffee, tea, soda, energy drinks, or chocolate.



Note to Caregiver: These are general instructions for a sleep study. Be sure to read the instructions from the prescribing physician or sleep study center in order to follow instructions specific to the individual.

Don't Take a Nap that Day

A sleep study works best when you're sleepy!

The doctor will probably tell you **NOT** to take a nap during the day of your test.



Eat Dinner Before You Go

It's hard to sleep when you are hungry, so be sure to eat dinner before you go.

Just remember—no food or drinks with caffeine!

That means no cola, coffee, tea, or chocolate!



Bathe Before You Go

If you shower in the evening, you will want to do this before going to the sleep center.

Make sure your hair is clean and dry.



What to Bring With You

Bring your comfortable pajamas. Do you have a favorite pillow or blanket? Do you have a book you like to read or soft music you like to listen to before you sleep?

You can bring anything with you that helps you to sleep.



Note to Caregiver: A button-down pajama top may be recommended if the sleep study requires sensors to be placed on the chest.

What to Bring With You

Bring your toothbrush and comb or brush with you so you can brush your teeth and hair before you go to bed and again when it's time to come home in the morning.

If you take medication at bedtime or in the morning, you will want to bring it with you, too.

(Name of caregiver) will help you take everything with you that you will need.

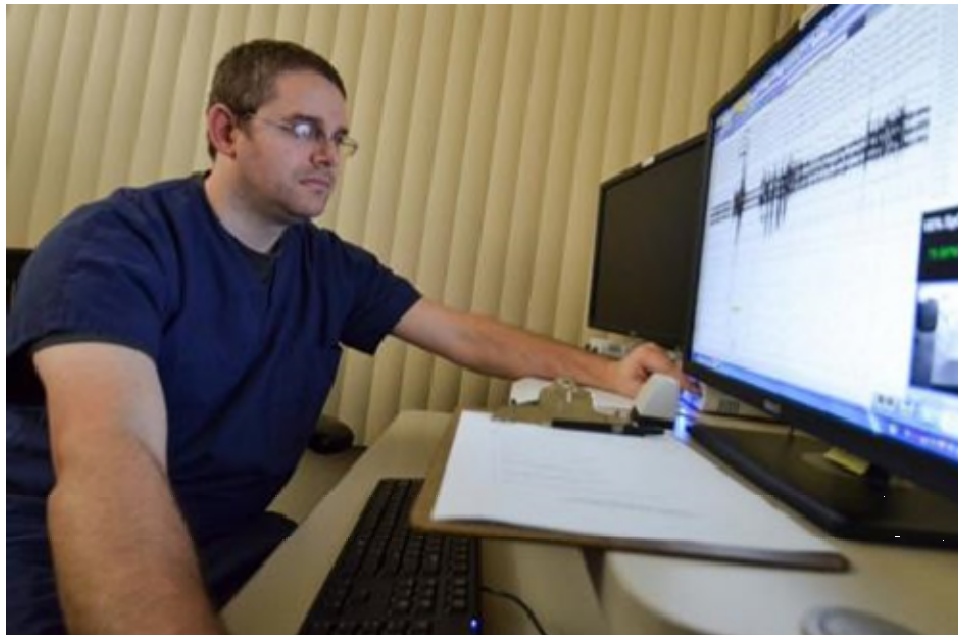


Note to Caregiver: Be sure to discuss the individual's need to take medications at bedtime and/or in the morning with the prescribing doctor/clinic prior to the day of the study. Bring the individual's medications to the study as directed by the physician.

The Sleep Center

When you first get to your appointment, you will meet the person who will be helping you. This person is called a technician.

You may also see what looks like many TVs in the room. These are called monitors. The technician watches these to see how you are sleeping.



Note to Caregiver: The employees at a sleep center may be referred to as “technicians.” Use the terminology with which the individual will be most familiar. If a person refers to anyone who works in similar places to be “nurses,” or “helpers,” or “caregivers,” you may wish to use these terms while reviewing this guide with the Individual.

Getting Hooked Up

After you are in your pajamas, the technician will put sticky patches, called electrodes, on your body.

These electrodes are like small stickers with wires attached. They feel just like band aids and won't hurt your skin at all.



Note to Caregiver: You may want to obtain plastic stickers that you can place on the individual's arm to help him/her better understand and prepare for how the electrodes will feel against the skin.

Getting Hooked Up

The technician will put electrodes on your head, your chest, your legs and even your finger.

(Name of caregiver) will be right there with you to assist you and make sure that you are all right.



Note to Caregiver: You may wish to reassure the individual again that the electrodes do not hurt, and that the technician is there to help (not hurt) him or her.

To Help You Breathe



This person is wearing a plastic tube in his nose called a nasal cannula. This helps a person to breathe better while they sleep.

Sometimes during a sleep study, you might have to wear one of these. If you need to wear one of these tubes for your test, the technician will tell you.

Wearing a nasal cannula doesn't hurt at all.

Note to Caregiver: *The sleep study instructions will most likely indicate whether or not the individual has to wear a nasal cannula. If you have any questions, contact the prescribing doctor/clinic before the test to help better prepare the individual.*

To Help You Breathe



This person is wearing a mask over his face called a CPAP mask. This helps a person to breathe better when they sleep.

Sometimes during a sleep study, you might have to wear one of these masks. If you need to wear one of these masks for your test, the technician will tell you.

Wearing a CPAP mask doesn't hurt at all.

Note to Caregiver: *Note to Caregiver: The sleep study instructions will most likely indicate whether or not the individual has to wear a CPAP mask. If you have any questions, contact the prescribing doctor/clinic before the test to help better prepare the individual.*

A Special Belt



This person is wearing a special belt. This belt helps the technician know how well a person is breathing when they sleep.

Sometimes during a sleep study, you might have to wear a special belt like this. If you need to wear one for your test, the technician will tell you.

Wearing a special belt like this doesn't hurt at all.

Note to Caregiver: *The sleep study instructions will most likely indicate whether or not the individual has to wear an elastic belt(s) to measure breathing effort. If you have any questions, contact the prescribing doctor/clinic before the test to help better prepare the individual.*

If You Have to Use the Bathroom

If you have to use the bathroom at night, let the technician know and he or she will help you.



Note to Caregiver: You may wish to let the individual know the technician will hear them if they ask for help and will remove the wires, breathing apparatus, etc. if they need to get up during the night.

Time for Bed!



Now, all you have to do is go to sleep!

When you wake up in the morning, your sleep study will be over, and (name of caregiver) will be there to take you home!

Great Job! I know You Can Do It!

See? It's that simple!

I know you can do it! You always do a great job!



Note to Caregiver: Now is a good time to assess whether the individual understands the process and is able to discuss with you what will happen during a sleep study. Ask the individual if he/she has any questions. This information may have to be rehearsed several times prior to the study to help the individual fully prepare for this test. Be sure to be encouraging and to offer praise to the person each time you rehearse this guide.

Resources

- Breus, M.J., (2017, September 14). What's it like to take a sleep study? Retrieved from <https://www.thesleepdoctor.com/2017/09/14/whats-like-take-sleep-study>
- Polysomnography (sleep study). (2018, November 17). Retrieved from <https://www.mayoclinic.org/tests-procedures/polysomnography/about/pac-20394877>
- Sleep.org (2020). What Happens during a Sleep Study. Retrieved from <https://www.sleep.org/articles/what-happens-during-sleep-study/>



For additional information regarding this guide or any of our physical or behavioral health trainings, contact:

**Kepro SW PA Health Care Quality Unit
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